

DMH Satisfaction Survey Results

Consumer Satisfaction - 2002

Family Directed Support

Introduction

Missouri's Family Directed Supports (MFDS) was established in July, 1998, by the Missouri Division of Mental Retardation and Developmental Disabilities as part of an overall system redesign initiative aimed at supporting families caring for a member with a developmental disability in their home. Incorporating the values and principles of family support, Missouri's Family Directed Supports emphasizes the responsibility and authority of families in planning, developing, and accessing the unique supports they need.

The survey looked at the impact of the Family Directed Support program on families. The purpose of the survey was to solicit opinions from participants as to how the program has affected their family. The second portion of the survey asked families to describe other issues or events that impact their family's life. This report will describe the findings of the survey.

Methodology

All families that received services under the Family Directed Support program (9623 families) were mailed survey forms. One thousand four hundred and thirteen forms were returned, for a return rate of 14.7%.

Demographics of the Sample

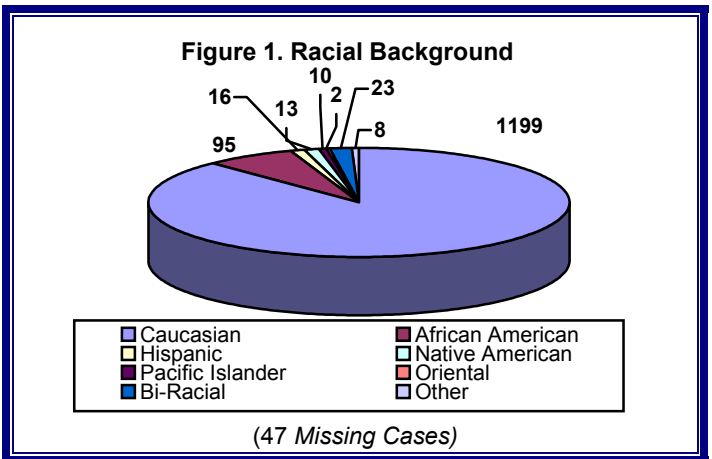
The survey looked at the age of the family member who was receiving services, the relationship of the person who completed the survey to the consumer, and whether a Support Agreement had been approved or signed. There were many instances where the respondent did not complete the demographic information. The frequencies of these demographics will be presented.

Gender of Recipient

Families reported more males served (59.8%) than females (40.2%).

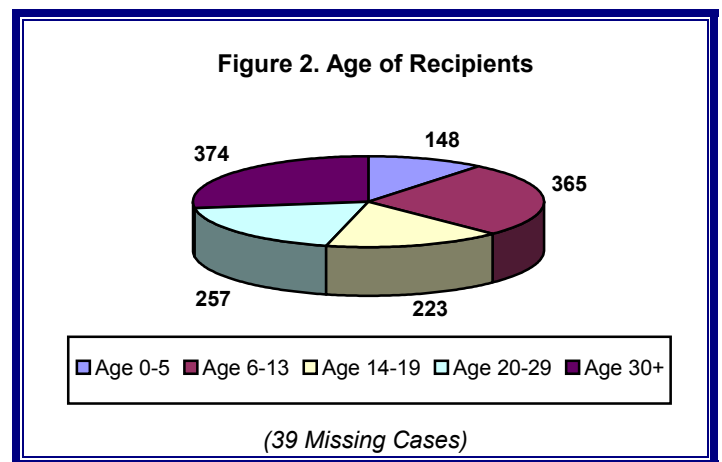
Racial Background

The majority of the families were Caucasian (87.8%). There were 95 families (7.0%) who were African American, 16 families (1.2%) who were Hispanic, 13 families (1.0%) who were Native American, 10 families (0.7%) who were Pacific Islanders, 2 families (0.1%) who were Oriental, 23 families (1.7%) who were Bi-Racial, and 8 families who noted an "other" racial background (0.6%). (See Figure 1.)



Age of the Recipient

The age of the family member was listed on the form. When two family members' ages were listed, the oldest was used. The mean age was 22.12 years. Figure 2 presents the age distribution.



Satisfaction with Services

Overall both families in the regular Division of MR/DD sample and in the FDS (Family Directed Support) sample were satisfied with the services (means of 4.11 and 3.93 respectfully). Families in the MR/DD only group were most satisfied with the staff keeping information confidential while the FDS families were most satisfied with the staff's respect of ethnic and cultural backgrounds. Families in the MR/DD only group were least satisfied with how much the staff know about how to get things done while the FDS families were least satisfied with services being provided in a timely manner. See Table 1.

Table 1 - Satisfaction with Services (Part 1)

How happy are you . . .	Total State (MRDD only)	Total State (FDS only)	Albany (MRDD only)	Albany (FDS only)	Central (MRDD only)	Central (FDS only)	Hannibal (MRDD only)	Hannibal (FDS only)	Joplin (MRDD only)	Joplin (FDS only)	Kansas City (MRDD only)	Kansas City (FDS only)
1. with the people who are paid to support your family member?	4.06 (106)	4.10 (1268)	4.25 (8)	4.00 (85)	5.00 (3)	4.25 (79)	4.50 (8)	4.33 (57)	4.17 (6)	4.15 (79)	4.00 (19)	3.95 (62)
2. with how much your family member's support staff know about how to get things done?	3.97 (106)	3.94 (1292)	4.38 (8)	3.99 (86)	5.00 (3)	4.16 (81)	4.63 (8)	4.30 (61)	3.83 (6)	4.13 (80)	3.85 (20)	3.90 (61)
3. with how staff and/or case manager keeps things about your family member and his/her life confidential?	4.35 (106)	4.30 (1297)	4.38 (8)	4.29 (89)	5.00 (3)	4.51 (84)	4.75 (8)	4.65 (60)	4.40 (5)	4.37 (83)	4.15 (20)	4.34 (61)
4. that your family member's plan has what he/she wants in it?	4.03 (106)	3.89 (1302)	4.38 (8)	3.91 (91)	5.00 (3)	4.16 (85)	4.38 (8)	4.26 (62)	3.83 (6)	4.15 (80)	3.79 (19)	3.72 (60)
5. with how the case manager and support people are doing what your family member's plan says they should do?	4.12 (108)	3.97 (1314)	4.38 (8)	4.01 (91)	5.00 (3)	4.23 (88)	4.75 (8)	4.40 (63)	3.80 (5)	4.22 (82)	3.68 (22)	3.84 (61)
6. that the staff who provide services to your family member respect his/her ethnic and cultural background?	4.30 (96)	4.33 (1209)	4.29 (7)	4.20 (84)	4.33 (3)	4.49 (80)	4.75 (8)	4.61 (57)	4.60 (5)	4.54 (74)	4.00 (21)	4.50 (54)
7. with the supports and services that your family member receives from this Regional Center?	4.11 (108)	3.93 (1347)	4.38 (8)	3.97 (91)	4.33 (3)	4.18 (85)	4.63 (8)	4.27 (63)	4.25 (4)	4.15 (80)	3.82 (22)	3.76 (63)
8. that services to your family member are provided in a timely manner?	4.05 (110)	3.84 (1351)	4.13 (8)	3.99 (90)	4.33 (3)	4.22 (86)	4.63 (8)	4.25 (64)	3.67 (6)	3.98 (84)	3.91 (22)	3.84 (63)
9. with your family member's case manager?	4.16 (108)	4.09 (1358)	4.38 (8)	4.16 (91)	4.33 (3)	4.34 (88)	4.88 (8)	4.45 (65)	4.00 (6)	4.31 (81)	3.65 (20)	3.90 (62)
The first number represents a mean rating. Scale: 1=Not at all satisfied . . . 5=Very satisfied. The number in parentheses represents the number responding to this item.												

Table 1 - Satisfaction with Services (Part 2)

How happy are you . . .	Kirksville (MRDD only)	Kirksville (FDS only)	Poplar Bluff (MRDD only)	Poplar Bluff (FDS only)	Rolla (MRDD only)	Rolla (FDS only)	Sikeston (MRDD only)	Sikeston (FDS only)	Spring- field (MRDD only)	Spring- field (FDS only)	St. Louis (MRDD only)	St. Louis (FDS only)
1. with the people who are paid to support your family member?	4.71 (7)	4.13 (69)	3.71 (7)	4.14 (50)	4.17 (6)	4.24 (152)	2.67 (3)	4.12 (60)	4.44 (9)	4.16 (141)	3.73 (30)	3.99 (434)
2. with how much your family member's support staff know about how to get things done?	4.67 (6)	4.03 (69)	4.00 (7)	4.08 (50)	4.00 (6)	4.12 (159)	2.67 (3)	3.81 (59)	4.22 (9)	3.92 (142)	3.67 (30)	3.75 (444)
3. with how staff and/or case manager keeps things about your family member and his/her life confidential?	4.71 (7)	4.16 (70)	3.71 (7)	4.28 (53)	4.33 (6)	4.47 (160)	3.33 (3)	4.34 (59)	4.67 (9)	4.37 (143)	4.30 (30)	4.12 (435)
4. that your family member's plan has what he/she wants in it?	4.86 (7)	4.04 (70)	3.71 (7)	4.04 (52)	4.33 (6)	4.15 (154)	3.33 (3)	3.93 (58)	4.44 (9)	4.02 (141)	3.70 (30)	3.59 (449)
5. with how the case manager and support people are doing what your family member's plan says they should do?	4.86 (7)	4.10 (72)	3.86 (7)	3.92 (53)	4.50 (6)	4.19 (161)	3.33 (3)	4.08 (60)	4.38 (8)	4.10 (145)	4.00 (31)	3.66 (438)
6. that the staff who provide services to your family member respect his/her ethnic and cultural background?	4.75 (4)	4.29 (66)	3.67 (3)	4.33 (52)	4.40 (5)	4.43 (148)	3.00 (3)	4.28 (53)	4.56 (9)	4.38 (134)	4.39 (28)	4.18 (407)
7. with the supports and services that your family member receives from this Regional Center?	5.00 (7)	4.01 (71)	4.14 (7)	3.98 (54)	4.33 (6)	4.28 (165)	3.33 (3)	4.10 (59)	4.67 (9)	3.97 (145)	3.74 (31)	3.65 (471)
8. that services to your family member are provided in a timely manner?	5.00 (7)	4.14 (70)	4.00 (7)	3.87 (53)	4.33 (6)	4.06 (165)	3.00 (3)	4.00 (60)	4.11 (9)	3.84 (147)	3.87 (31)	3.51 (469)
9. with your family member's case manager?	5.00 (7)	4.16 (73)	4.14 (7)	3.98 (54)	4.33 (6)	4.26 (164)	3.67 (3)	4.20 (60)	4.56 (9)	4.30 (148)	3.97 (31)	3.83 (472)
<p>The first number represents a mean rating.</p> <p>Scale: 1=Not at all satisfied . . . 5=Very satisfied.</p> <p>The number in parentheses represents the number responding to this item.</p>												

Satisfaction with Quality of Life

Families in both the MR/DD only group and in the FDS group were most satisfied with safety in the home. Families in the MR/DD only group were least satisfied with how their family member spends his/her spare time while the FDS families were least satisfied with the opportunities/chances their family member had to make friends. See Table 2.

Table 2 - Satisfaction with Quality of Life (Part 1)

How happy are you . . .	Total State (MRDD only)	Total State (FDS only)	Albany (MRDD only)	Albany (FDS only)	Central (MRDD only)	Central (FDS only)	Hannibal (MRDD only)	Hannibal (FDS only)	Joplin (MRDD only)	Joplin (FDS only)	Kansas City (MRDD only)	Kansas City (FDS only)
10. with how your family member spends his/her day?	4.08 (111)	3.80 (1344)	4.63 (8)	3.73 (90)	5.00 (3)	3.90 (87)	4.25 (8)	3.94 (63)	4.17 (6)	3.94 (77)	3.96 (23)	3.89 (62)
11. with where your family member lives?	4.32 (110)	4.39 (1290)	4.63 (8)	4.13 (82)	5.00 (3)	4.38 (82)	4.50 (8)	4.37 (63)	4.50 (6)	4.36 (69)	4.41 (22)	4.47 (59)
12. with the number of choices your family member has in his/her life?	4.09 (106)	3.66 (1299)	4.50 (8)	3.73 (85)	4.67 (3)	3.81 (84)	4.50 (8)	3.89 (64)	4.20 (5)	3.71 (75)	3.86 (21)	3.63 (57)
13. with the opportunities/chances your family member has to make friends?	4.04 (109)	3.56 (1315)	4.50 (8)	3.62 (89)	5.00 (3)	3.81 (86)	4.38 (8)	3.63 (62)	4.00 (5)	3.65 (77)	3.83 (23)	3.49 (57)
14. with your family member's health care?	4.27 (110)	4.10 (1328)	4.50 (8)	3.97 (87)	5.00 (3)	4.23 (87)	4.50 (8)	4.13 (62)	4.00 (5)	3.93 (75)	3.83 (23)	3.95 (62)
15. with what your family member does during his/her free time?	3.95 (111)	3.59 (1304)	4.50 (8)	3.63 (88)	5.00 (3)	3.88 (84)	4.50 (8)	3.75 (63)	3.67 (6)	3.74 (74)	3.74 (23)	3.46 (61)
16. with the opportunities your family member has had during the last year to do something that he/she is proud of?	4.03 (104)	3.84 (1273)	4.38 (8)	3.78 (89)	5.00 (3)	4.04 (84)	4.38 (8)	4.07 (60)	3.80 (5)	4.07 (76)	3.68 (19)	3.71 (55)
How safe do you feel ...												
17. your family member is in his/her home?	4.47 (107)	4.55 (1360)	4.13 (8)	4.41 (90)	5.00 (3)	4.70 (88)	4.38 (8)	4.58 (64)	4.50 (6)	4.61 (77)	4.36 (22)	4.45 (62)
18. your family member is in his/her neighborhood?	4.37 (105)	4.24 (1346)	4.38 (8)	4.19 (91)	5.00 (3)	4.42 (88)	4.50 (8)	4.33 (64)	4.50 (6)	4.27 (77)	4.29 (21)	4.16 (62)
The first number represents a mean rating. Scale: (<i>how satisfied are you...</i>): 1=Not at all satisfied . . . 5=Very satisfied. Scale: (<i>how safe do you feel...</i>): 1=Not at all safe . . . 5=Very safe. The second number represents the number responding to this item.												

Table 2 - Satisfaction with Quality of Life (Part 2)

How happy are you . . .	Kirksville (MRDD only)	Kirksville (FDS only)	Poplar Bluff (MRDD only)	Poplar Bluff (FDS only)	Rolla (MRDD only)	Rolla (FDS only)	Sikeston (MRDD only)	Sikeston (FDS only)	Spring- field (MRDD only)	Spring- field (FDS only)	St. Louis (MRDD only)	St. Louis (FDS only)
10. with how your family member spends his/her day?	4.43 (7)	3.75 (75)	4.00 (7)	3.79 (53)	4.00 (6)	3.93 (160)	4.00 (3)	3.80 (59)	4.22 (9)	3.80 (142)	3.81 (31)	3.71 (476)
11. with where your family member lives?	4.71 (7)	4.36 (74)	4.00 (7)	4.36 (53)	4.83 (6)	4.61 (155)	4.67 (3)	4.41 (58)	4.22 (9)	4.43 (135)	3.90 (31)	4.34 (460)
12. with the number of choices your family member has in his/her life?	4.71 (7)	3.71 (72)	3.86 (7)	3.83 (53)	4.50 (6)	3.86 (154)	3.67 (3)	3.55 (58)	4.22 (9)	3.75 (137)	3.79 (29)	3.47 (460)
13. with the opportunities/ chances your family member has to make friends?	4.60 (5)	3.70 (70)	4.00 (7)	3.82 (50)	4.33 (6)	3.81 (154)	3.33 (3)	3.48 (58)	4.22 (9)	3.60 (141)	3.78 (32)	3.35 (471)
14. with your family member's health care?	4.86 (7)	4.05 (75)	4.29 (7)	4.24 (55)	5.00 (6)	4.20 (159)	4.33 (3)	4.29 (55)	4.56 (9)	4.16 (145)	4.10 (31)	4.07 (466)
15. with what your family member does during his/her free time?	4.50 (6)	3.78 (73)	4.00 (7)	3.75 (52)	4.17 (6)	3.78 (151)	3.33 (3)	3.55 (55)	4.00 (9)	3.71 (140)	3.69 (32)	3.35 (463)
16. with the opportunities your family member has had during the last year to do something that he/she is proud of?	5.00 (5)	3.97 (70)	4.00 (6)	3.94 (49)	4.50 (6)	3.90 (144)	3.33 (3)	3.77 (53)	4.00 (9)	3.83 (141)	3.84 (32)	3.73 (452)
How safe do you feel ...												
17. your family member is in his/her home?	4.80 (5)	4.49 (74)	4.29 (7)	4.55 (55)	4.67 (6)	4.68 (161)	4.67 (3)	4.61 (62)	4.63 (8)	4.57 (143)	4.48 (31)	4.50 (484)
18. your family member is in his/her neighborhood?	4.75 (4)	4.31 (71)	4.29 (7)	4.28 (54)	4.67 (6)	4.50 (158)	4.33 (3)	4.56 (61)	4.63 (8)	4.21 (137)	4.16 (31)	4.09 (483)
<p>The first number represents a mean rating. Scale: (<i>how satisfied are you...</i>): 1=Not at all satisfied . . . 5=Very satisfied. Scale: (<i>how safe do you feel...</i>): 1=Not at all safe . . . 5=Very safe. The second number represents the number responding to this item.</p>												

Impact of the Program on Family Life

The family members were asked to rate how their life had changed in each of fifteen areas as a result of their participation in Missouri's Family Directed Support Program. The families were asked to rate this change on a five point scale (1=*a lot worse*; 2=*a little worse*; 3=*no change*; 4=*a little better*; 5=*a lot better*). Means were calculated for each of the responses as well as the frequency distribution of the responses.

Overall

One question asked how their family's life overall had changed. The mean for this item was 4.06. Seventy-four percent of those who responded reported that their life was at least *a little better*. Over one-third of the respondents noted that it was *a lot better* (36.4%). (See Figure 3.)

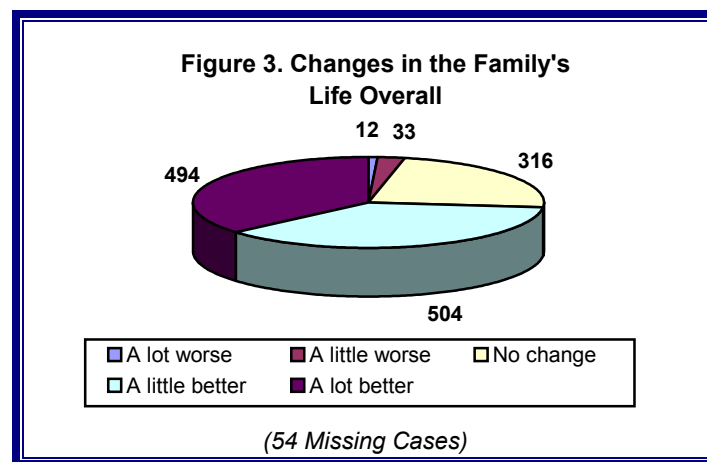
Family Functioning

Four items examined the ability of the family to function. These included (1) family's ability to do more together; (2) the stress in the family's life; (3) the family's ability to be more like other families; and (4) financial worries. Table 3 presents the results.

Table 3. Changes in Family Functioning

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your Family's ability to do more together	15 (1.1%)	50 (3.7%)	488 (36.4%)	409 (30.5%)	378 (28.2%)	3.81
The stress in your family's life	44 (3.3%)	94 (7.0%)	408 (30.3%)	473 (35.1%)	327 (24.3%)	3.70
Your family's ability to be more like other families	25 (1.9%)	60 (4.5%)	536 (40.2%)	418 (31.4%)	294 (22.1%)	3.67
Your financial worries	71 (5.3%)	123 (9.1%)	527 (39.0%)	363 (26.9%)	267 (19.8%)	3.47

^aScale: 1 = a lot worse.....5 = a lot better



The item with the highest mean was the family's ability to do more together. This item showed a mean change of 3.81, indicating that it was *a little better* than before. The other items in this category were also slightly improved for at least 50% of the respondents.

The means for the respondents of each Regional Center were calculated. (See Table 4.)

Table 4. Regional Center Means of Changes in Family Functioning

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family's ability to do more together	3.64 (90)	3.64 (72)	3.89 (63)	3.85 (60)	3.91 (82)	3.79 (145)
The stress in your family's life	3.60 (89)	3.52 (73)	3.78 (65)	3.78 (60)	3.78 (83)	3.74 (145)
Your family's ability to be more like other families	3.57 (89)	3.46 (71)	3.86 (65)	3.55 (60)	3.85 (81)	3.73 (144)
Your financial worries	3.30 (88)	3.51 (74)	3.41 (64)	3.55 (60)	3.49 (81)	3.34 (142)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family's ability to do more together	3.94 (161)	4.04 (55)	3.80 (59)	3.75 (465)	3.94 (88)	3.81 (1340)
The stress in your family's life	3.84 (160)	3.73 (55)	3.77 (61)	3.63 (466)	3.76 (89)	3.70 (1346)
Your family's ability to be more like other families	3.87 (162)	3.89 (54)	3.70 (60)	3.55 (457)	3.76 (90)	3.67 (1333)
Your financial worries	3.64 (163)	3.64 (55)	3.43 (60)	3.39 (474)	3.77 (90)	3.47 (1351)
^a Scale: 1 = a lot worse.....5 = a lot better						

Caring for Family Member

The survey looked at the ability of the family to care for the family member. There were two items that related to this category: (1) ability to care for family member; and (2) worries about family member's future well being (see Table 5 for the results).

Table 5. Changes in Caring for Family Member

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your ability to care for your family member	17 (1.3%)	45 (3.4%)	408 (30.4%)	426 (31.8%)	444 (33.1%)	3.92
Your worries about your family member's future well being	63 (4.7%)	132 (9.7%)	474 (35.0%)	420 (31.0%)	265 (19.6%)	3.51
^a Scale: 1 = a lot worse.....5 = a lot better						

The families perceived at least a slight change for the better on the first of these items. For the item about caring for their family member, 33.1% noted *a lot better* situation now. For worrying about their family member's future well being, only 19.6% of the respondents noted a lot of improvement.

The means by Regional Center were calculated for changes in caring for family members. (See Table 6.)

Table 6. Regional Center Means of Changes in Caring for Family Member

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your ability to care for your family member	3.79 (89)	3.88 (72)	3.91 (64)	3.83 (60)	4.13 (80)	4.01 (142)
Your worries about your family member's future well being	3.38 (92)	3.56 (73)	3.69 (65)	3.52 (60)	3.64 (80)	3.40 (144)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your ability to care for your family member	4.15 (158)	4.05 (56)	4.08 (60)	3.76 (471)	4.10 (88)	3.92 (1340)
Your worries about your family member's future well being	3.80 (161)	3.69 (55)	3.49 (61)	3.34 (473)	3.82 (90)	3.51 (1354)
^a Scale: 1 = a lot worse.....5 = a lot better						

Families' Ability to Do Activities

The literature has often reported that families of individuals with developmental disabilities have more difficulty maintaining a social life. The survey looked at several items that related to this category. First was the family's ability to do things that they were unable to do before. The second related to the family's ability to get to know other people in the community. The third item focused on the family's level of inclusion in the community (see Table 7).

Table 7. Changes in the Families' Ability to do Activities

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean ^a
Your ability to do things that you were unable to do before	24 (1.8%)	63 (4.7%)	499 (36.9%)	433 (32.0%)	334 (24.7%)	3.73
Your ability to get to know other people in your community	17 (1.3%)	38 (2.8%)	714 (52.8%)	360 (26.6%)	222 (16.4%)	3.54
Your family's level of inclusion in the community	23 (1.7%)	36 (2.7%)	733 (54.8%)	346 (25.9%)	199 (14.9%)	3.50
^a Scale: 1 = a lot worse.....5 = a lot better						

The Family Support Program had a larger impact on the families' ability to do things they were unable to do before than the other categories. Nearly 60% of the respondents noted that this had changed for the better since participating in the program. The item that showed the least amount of positive change was the family's level of inclusion in the community. Here only 14.9% noted that it was *a lot better*.

The analyses for the changes in the family category can be found on Table 8.

Table 8. Regional Center Means of Changes in the Families' Ability to do Activities

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your ability to do things that you were unable to do before	3.60 (91)	3.58 (73)	3.74 (65)	3.73 (59)	3.87 (83)	3.79 (145)
Your ability to get to know other people in your community	3.36 (90)	3.54 (74)	3.58 (65)	3.32 (60)	3.65 (82)	3.61 (145)
Your family's level of inclusion in the community	3.32 (91)	3.49 (74)	3.59 (64)	3.35 (60)	3.48 (81)	3.51 (140)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your ability to do things that you were unable to do before	3.97 (162)	3.87 (55)	3.72 (60)	3.62 (470)	3.82 (90)	3.73 (1353)
Your ability to get to know other people in your community	3.74 (159)	3.82 (55)	3.56 (61)	3.43 (470)	3.69 (90)	3.54 (1351)
Your family's level of inclusion in the community	3.61 (157)	3.76 (55)	3.41 (59)	3.46 (467)	3.57 (89)	3.50 (1337)
^a Scale: 1 = a lot worse.....5 = a lot better						

Family's Well Being

There were two items on the survey that related to the family's well being. One concerned their emotional well being and the other their physical health (see Table 9).

Table 9. Changes in the Family's Well Being

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your family's emotional well being	21 (1.6%)	67 (5.0%)	473 (35.1%)	485 (36.0%)	301 (22.3%)	3.73
Your family's physical well being	26 (1.9%)	87 (6.4%)	654 (48.4%)	337 (24.9%)	248 (18.3%)	3.51
^a Scale: 1 = a lot worse.....5 = a lot better						

The respondents noted a larger positive change in their emotional well being than in their physical health. The mean of the former was 3.73, with over 58% noting a change for the better, while the latter mean was 3.51, with only 43.2% reporting this change. Table 10 presents these analyses by regional centers.

Table 10. Regional Center Means of Changes in Family's Well Being

<i>Item:</i>	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family's emotional well being	3.53 (90)	3.67 (73)	3.91 (65)	3.64 (59)	3.73 (81)	3.79 (145)
Your family's physical well being	3.43 (91)	3.55 (73)	3.71 (65)	3.53 (59)	3.47 (81)	3.49 (145)
<i>Item:</i>	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family's emotional well being	3.92 (159)	3.89 (55)	3.80 (60)	3.61 (470)	3.90 (90)	3.73 (1347)
Your family's physical well being	3.69 (159)	3.55 (56)	3.65 (60)	3.40 (473)	3.67 (90)	3.51 (1352)
^a Scale: 1 = a lot worse.....5 = a lot better						

Family Members' Well Being

The impact on the family members' well being was reported to be less than the impact on the family's well being (See Table 11).

Table 11. Changes in the Family Members' Well Being

<i>Item:</i>	A Lot Worse	A Little Worse	No Change	A Little Better	A Lot Better	Mean^a
Your family members' emotional well being	22 (1.6%)	82 (6.1%)	461 (34.1%)	458 (33.9%)	330 (24.4%)	3.73
Your family members' level of inclusion in the community	23 (1.7%)	55 (4.1%)	633 (47.3%)	381 (28.5%)	247 (18.4%)	3.58
Your family members' growth and development	28 (2.1%)	47 (3.5%)	423 (31.4%)	509 (37.7%)	342 (25.4%)	3.81
^a Scale: 1 = a lot worse.....5 = a lot better						

Many of the families reported no change occurring in these items. This was particularly true for the family members' community inclusion. Here, over 45% of the families reported no change with an additional 6% reporting a negative impact. See Table 12 for the regional center analyses.

Table 12. Regional Center Means of Changes in Family Members' Well Being

Item:	1 Albany	2 Kirksville	3 Hannibal	4 Kansas City	5 Joplin	6 Springfield
Your family member's emotional well being	3.60 (91)	3.58 (73)	3.94 (65)	3.60 (60)	3.87 (83)	3.76 (145)
Your family member's level of inclusion in the community	3.44 (90)	3.49 (73)	3.67 (64)	3.32 (60)	3.78 (79)	3.68 (144)
Your family member's growth and development	3.73 (92)	3.71 (72)	3.94 (65)	3.76 (59)	3.93 (80)	3.83 (145)
Item:	7 Rolla	8 Poplar Bluff	9 Sikeston	10 St. Louis	11 Central	Total State
Your family member's emotional well being	3.91 (159)	3.95 (56)	3.79 (61)	3.62 (470)	3.89 (90)	3.73 (1353)
Your family member's level of inclusion in the community	3.66 (157)	3.73 (56)	3.49 (61)	3.52 (465)	3.64 (90)	3.58 (1339)
Your family member's growth and development	3.99 (160)	3.88 (56)	3.77 (61)	3.71 (470)	3.97 (89)	3.81 (1349)
<i>^aScale: 1 = a lot worse.....5 = a lot better</i>						

Impact of Age of Family Member on Responses

An analysis was conducted to determine if the age of the family member was related to the responses of the family. The age of the family member was divided into two categories: (1) those under 21 years of age; and (2) those 21 years of age and older. There were four significant responses based on age (see Table 13). The families of Children/Youth were more satisfied with their family's life overall, their family's ability to do more together, their family's ability to be more like other families and with their family member's growth and development.

Table 13. Comparison of Responses by Age of the Family Member^a

Item:	Children/Youth	Adults	Significance
Your family's life overall	4.13 (752)	3.98 (565)	F(1,1315)=9.207, p=.002
Your family's ability to do more together	3.89 (748)	3.72 (550)	F(1,1296)=10.187, p=.001
Your family's ability to be more like other families	3.72 (743)	3.62 (547)	F(1,1288)=3.949, p=.047
Your family members' growth and development	3.85 (751)	3.75 (557)	F(1,1306)=4.039, p=.045
<i>^aScale: 0 = a lot worse.....4 = a lot better</i>			

Other Issues or Events that Impact the Family's Life

The Consumer Satisfaction Survey for the families receiving Family Directed Support Services requested families to identify issues or events that impact their family's life. Responses to this inquiry ranged from personal stresses and family problems like divorce, feelings of isolation, and family member illness. Families described some of these issues and events in this way:

- *Divorce and issues that arise within the family*
- *Isolation - There are few families that we know with a child like ours*
- *Having a mentally disabled child is very stressful at times especially when his behavior is uncontrollable.*
- *Mother is ill making it hard to get family member to and from some activities*
- *Another older child with disabilities whom we have been unsuccessful in obtaining support for*
- *My husband is visually impaired*

Access to Services

A number of individuals who filled out the survey focused on a family's ability to access the services they need. Families indicated that waiting for eligibility is often times problematic. One person had this to say, *not being able to get into a day program because we are not waiver eligible, A_____ has been out of school for two years.* Another individual had this to say about the lack of services available to them once their child reached the age of three, *My son turned 3 in December and we were promptly told that the only services that he was eligible for was service coordination. With all due respect he receives no services to coordinate.* Still other issues in regard to accessing services had to do with having more options when it came to choosing therapists. Often times families find that the needs of their child requires a specialized type of therapy or at the very least a therapist with experience working with a specific disability. One family member had this to say about the need for specialized services, *Suitable healthcare to deal with my son's neurological problems; not enough choices for therapists (P.T., O.T., S.T.).*

Transportation

Transportation is an area that continues to be problematic for people with disabilities and for those that support and advocate for persons with disabilities. Finding reliable, safe, and accessible transportation continues to be a concern and is mentioned frequently in the Family Directed Support Surveys. Family members indicated that the lack of transportation creates a burden for those that care for persons with disabilities. One individual had this to say about their own experience, *The lack of good transportation that is a great handicap to me and W_____ getting around to places of importance to us.* Another parent commented on the unavailability of accessible transportation, *not having the right transportation to take my child and his wheelchair anywhere.*

Staff Turnover

Staff turnover and the inconsistencies caused by continuously changing staff is an ongoing problem in the human service field. Many families and consumers indicated that staff turnover is a problem and something that needs to be improved upon. Repeatedly throughout the Consumer Satisfaction Surveys, staff turnover was an issue that showed up many times. Certainly no one would disagree that continuously changing staff can cause problems for people who receive services. Interestingly enough one family expressed that staff turnover not only effects the person with a disability but that it affects the entire family significantly. In response to the question that asked families to identify significant events and issues that affect their family, someone had this to say, *Problem with staff changing has a major impact on entire family.* Another expressed their concern over staff turnover by saying, *something has to be done about the constantly changing staff.*

Decrease in Services / Loss of Services

A number of families indicated that the changing climate of the economy and the recent budget cuts have caused a great deal of hardship for families who were at one time receiving services and now find themselves having to pay for those same services solely on their own. *The first 2 years were great dealing with FDS. But this past year we have been stuck with bills and services have been cut this will be hard on my family.* Another family member had this to say about budget cuts and the difficulty those cuts cause families, *Budget cuts and single income family and The need for some equipment (a lift for the bathroom) but I've been told the money isn't there.* Other respondents to the survey shared that the fear over whether or not services would continue to be available was a real concern that had an impact on family's lives. *We always worry that what services we receive will be taken away. What is in store for the future of our son?* And another individual said, *I fear that the services for my children will decline.*

Overall System Issues

Some families referred to "the system" as being problematic. Respondents identified some of the things they believed to be other issues that affected their family's lives. One individual said that, *The system and incompetence is overwhelming.* Another family member said that there seemed to be a *lack of understanding - very little knowledge of 'inclusion'.* Finally another individual felt that the system tended to segregate, *Tremendous amount of segregation.*

Children getting older

Growing older is simply a fact of life. Parents age and as such their needs change. The same goes for children. As a child with a disability ages and grows into adulthood their needs change as well. Often times parents of children with disabilities find themselves wondering how they will be able to care for their adult child as they themselves age but also how will they need to be supported differently as they age and continue to care for their adult child. In addition, parents often times wonder what will happen to their child after they are gone. Concerns over where their child will live and where they will receive financial support have a large impact on families. Families had these things to say about issues they face as children grow older and they themselves age. *As our child grows older what he will do as we grow older is a concern, We want our daughter to get used to living somewhere else so we can help her transition before we can't take care of her anymore, and who will take care of our child after we're gone.*

Respite

Respite Services was an issue that was brought up again and again by families. Many expressed that it was something they liked the best about the services they received. Others commented on it as an area that needed to be improved. Respite was also identified as an issue that impacted family life. Families had this to say about respite services, *Respite is always at arms length, too long of waiting lists - diminished funds for service so too expensive, so we don't use - too much of a hassle!*, and *As our daughter gets older, it is getting more and more difficult to find someone to provide respite care in our home.*